

# **North Dakota Real Choice Systems Change Grant Rebalancing Initiative**

Choice and Self-Directed Community Resource Delivery  
for the Elderly and People with Disabilities in North Dakota

## **Research Report One**

A Report of Focus Groups and Personal Interviews  
Conducted in North Dakota's Eight Human Service Regions with:

- Consumers of home and community based services,
- Elderly nursing home residents,
- Younger nursing home residents,
- Family members of consumers of continuum of care services, and
- Providers of continuum of care services

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The North Dakota Real Choice Systems Change Grant - Rebalancing Initiative, also called the Real Choice Rebalancing Grant (RCR), is a project funded by the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services. The North Dakota Department of Human Services-Aging Services Division was awarded the three year grant in September 2004. The Aging Services Division established a contract with the North Dakota Center for Persons with Disabilities (NDCPD) to carry out substantial portions of the grant's work scope. The North Dakota Center for Persons with Disabilities is a Center of Excellence at Minot State University. Its role is to apply the experience, knowledge, talent, and research expertise of the university to the challenges facing disability and human services in North Dakota. NDCPD engages in a wide range of research, training, dissemination, and technical assistance activities serving North Dakotans with disabilities, their families, those who work with them, and the agencies and systems serving them. NDCPD is a full member of the Association of University Centers on Disabilities (AUCD), a national network of disability research and training programs at leading universities throughout the country.

The overall goal of the Real Choice Systems Change Grants is to implement the Olmstead Decision and President Bush's New Freedom Initiative. On June 18, 2001, President Bush directed Federal agencies to work together to "tear down the barriers" to community living by developing a government-wide framework for helping provide elderly and people with disabilities the supports necessary to learn and develop skills, engage in productive work, choose where to live, and fully participate in community life. The

Olmstead Decision calls upon states to integrate people with disabilities and provide community-based services.

The purpose of the North Dakota Real Choice Systems Change Grant – Rebalancing Initiative is to take an in-depth look at the continuum of care system and how North Dakota can better implement the Olmstead Decision and the New Freedom Initiative. This project's consumer and stakeholder-dominated process will gather information and work to build consensus on three key issues:

1. a mechanism to rebalance state resources for services for the elderly, people with disabilities, and their families in strengthening self-directed services in communities;
2. a system to provide a single point of entry to services for the elderly and people with disabilities who are considering long-term home and community-based services and institutional services in North Dakota; and
3. practical and sustainable public information services for access to all long-term care services in North Dakota.

This project will also develop a plan and potential legislation for balancing resources and establishing a statewide mechanism for single point of entry to continuum of care services in North Dakota.

### **Purpose of Research**

Although a wealth of information is available from past studies related to North Dakota's continuum of care services, the grant's steering committee determined that it was

necessary to gather additional information. A series of statewide focus groups and in-home personal interviews were conducted by project staff during October, November, and December 2005. This research was conducted to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

The five population areas identified by the grant's planning and steering committees included:

1. consumers of home and community based services (HCBS),
2. elderly nursing home residents,
3. younger nursing home residents,
4. family members of consumers of continuum of care services, and
5. providers of continuum of care services.

The focus groups and personal interviews were used to suggest ways to develop a mechanism to balance state resources and strengthen choice and self-directed services in communities for the elderly, people with disabilities, and their families. This research was also conducted to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities in North Dakota.

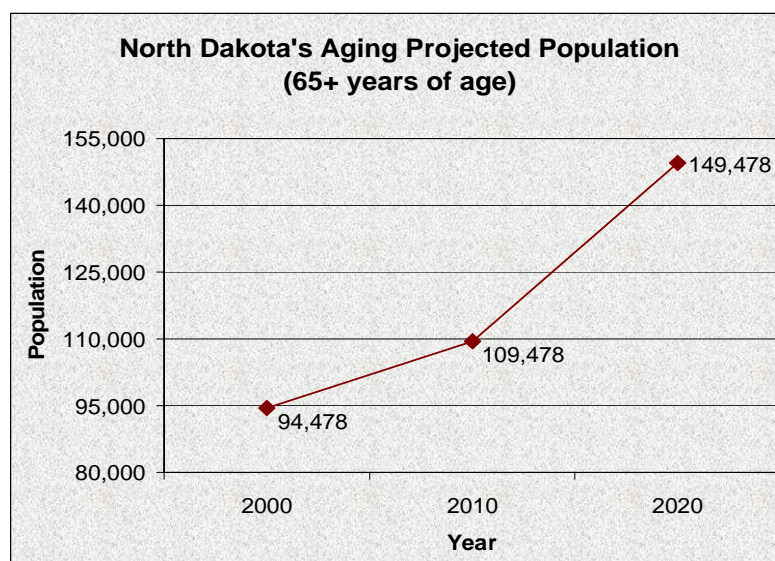
The data gathered will be used to complement what is already known about continuum of care services and to design a plan for North Dakota to better provide its long term services, programs, and activities in the most integrated settings appropriate to the needs of qualified

individuals with disabilities. The information gathered will be used to develop a plan for implementing Choice & Self-Directed Community Resource Delivery for the Elderly & People with Disabilities in North Dakota.

### Needs and Trends

- North Dakota is ranked first in the United States in the percentage of total population age 85 and older.
- North Dakota is ranked fifth in the United States in the percentage of the total population age 75 to 84 (AARP Public Policy Institute, Across the States: Profiles of Long-Term Care, 2004).
- If the trend continues, the number of elderly people in the state will increase by 58% over the next 20 years and will represent 23% of the state's population. (See figure 1)

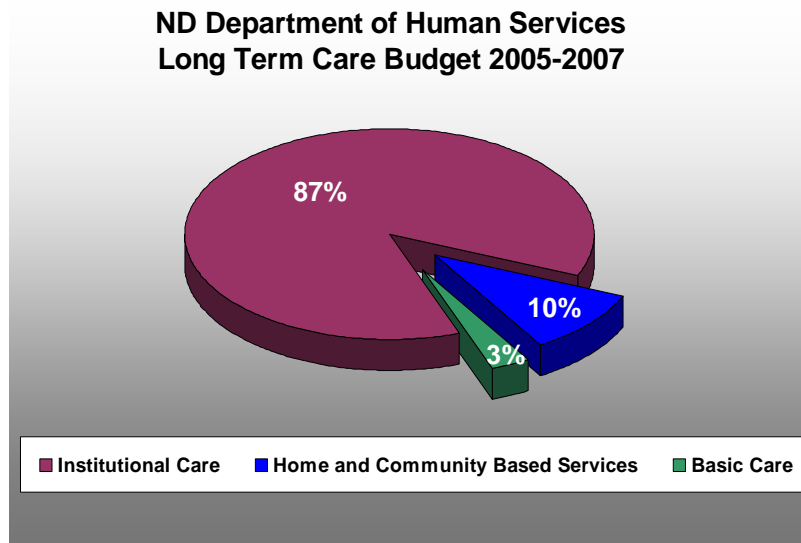
Figure 1



(Needs Assessment of Long Term Care, North Dakota: 2002, Initial Report & Policy Recommendations, November 2002, NDSU)

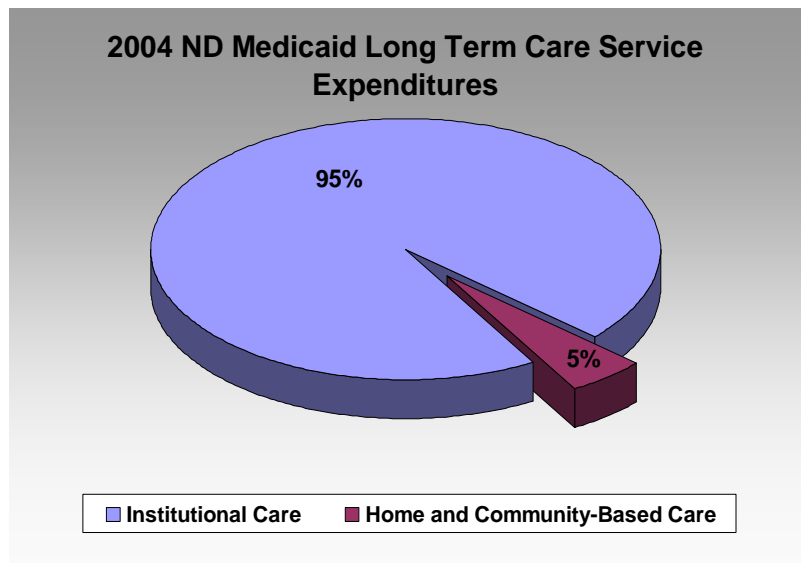
- North Dakota's 2005-2007 Department of Human Services Long Term Care budget assigns approximately: 3% to basic care, 10% to home and community based services, and 87% to institutional care. (See figure 2)

Figure 2



- North Dakota's 2004 distribution of Medicaid long term expenditures for aging and disability services were approximately 95% for institutional services (i.e. nursing home services) and approximately 5% for in home and community based services (i.e. home health services, personal care services, and HCBS waiver services for older adults and people with physical disabilities). (See figure 3)

Figure 3



(Brian Burwell, Kate Sredl, and Steve Eiken. May 2004. Medicaid Long-Term Care Expenditures in FY 2004.

- More than nine in ten North Dakota members rate having a range of support services available in their community to be *very* or *somewhat* important. More than three in four North Dakota members think it is *very* or *somewhat* important to provide funding to make support services widely available, even if it means an increase in taxes. (2004 AARP ND Member Survey: Support Services)

### Research Methods

The research study of the North Dakota Real Choice Rebalancing (RCR) Grant uses a mixed method approach allowing conclusions to be confirmed through triangulation. The mixed method approach includes focus groups, personal interviews, and questionnaires. These approaches identify and validate North Dakotans' current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term

care supports (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

This report describes the focus groups conducted in the fall of 2005, the scientific process of this research, and the findings. A focus group is “a carefully planned discussion designed to obtain perceptions and a defined area of interest in a permissive, non threatening environment. It is conducted with approximately seven to ten people by a skilled interviewer. The discussion is comfortable and often enjoyable for the participants as they share their ideas and perceptions” (Richard A. Krueger, *Focus groups: A Practical Guide for Applied Research*, 1988). This qualitative research methodology was combined with the use of personal interviews. The personal interviews were used to include participants with limited access to transportation and those who could not participate in focus groups for health reasons. Combining the results of the focus groups and personal interviews provides a rich description of how individual North Dakota citizens are experiencing the state’s continuum of care.

Quantitative questionnaires were also used as part of the project’s research plan to get a larger sample of data from certain populations. At the time this report is being written the questionnaire data is being gathered and analyzed. Through the process of data triangulation, each method will help to validate the emerging themes and conclusions. This report of the focus groups and personal interviews is only one piece of the entire research project. It does not include discussion or analysis of the data gathered through the quantitative (questionnaire) methods of the project. Future reports will include data analysis of the quantitative methods used and an analysis of the conclusions validated through the process of data triangulation.

## *Technique*

Prior to conducting the focus groups and personal interviews, the RCR planning and steering committees were consulted. Decisions about the participants, questions to be asked, and the random selection process for inviting participants were based on their recommendations. Throughout the development and implementation of the research project, the RCR planning and steering committees provided input and recommendations. This interactive process of committee review, input, recommendations, and research refinement was an important aspect of the project, helping to assure the validity of the resulting data. Additionally, this research project was reviewed and approved by the Minot State University Institutional Review Board, following all necessary procedures for the protection of human research subjects.

It was important for the focus groups and personal interviews to be conducted in rural and urban communities of North Dakota as recommended of the RCR planning and steering committees. Project staff coordinated with various regional providers and public entities to organize focus group locations, dates, and times in urban and rural communities (Focus group regional schedule Appendix A) (Map of Focus Groups and Personal Interviews Conducted, Appendix B). Because of limited grant funds, the focus groups were often held in locations where meeting room costs were minimal. Regional locations included centers for independent living, nursing homes, assisted living facilities, senior centers, and libraries. Each focus group meeting provided light refreshments for participants. The five population groups mentioned all consisted of adults over the age of 18. With the exception of providers, efforts were made to have at least one of each focus group type conducted in each of the eight human services

regions. As recommended by the RCR steering committee, the provider focus groups were not conducted in each region due to the fact that providers were able to give input on these issues through their strong representation on the RCR steering and stakeholder committees.

Providers were also strongly represented in other recent research regarding the continuum of care, such as the Needs Assessment of Long Term Care, North Dakota: 2002.

The criteria for selecting participants were identified by RCR steering committee members for each type of focus group (Participant Criteria Appendix C). In order to follow all HIPAA and privacy regulations, focus group invitations were sent to a designated number of participants in each of the eight human service regions through steering committee agencies (Steering Committee Membership Appendix D) and a randomly selected group of continuum of care provider agencies. These provider agencies included regional Older Americans Act providers, nursing homes, assisted living facilities, senior centers, Regional Aging Services Program Administrators (RASPs), centers for independent living, home health providers, and county case managers.

Many providers were aware of the regional focus groups and several requested the opportunity to attend, participate, or invite others to participate. In such situations, the principal investigator explained that the focus groups were not intended to be town hall meetings or public hearings and that participants were selected according to specific criteria to assure a representative cross-section of constituents. In the case of the regional provider focus groups, participants were randomly invited.

The randomly selected group of providers located in each region was sent an information packet approximately two to three weeks prior to the date of the focus group. The

packet included a cover letter (Appendix E), an overview of the project, directions for inviting participants, invitation letters, postage paid envelopes, and participant selection criteria. Providers were asked to consider the participant criteria and times and locations of the focus groups in their region as they considered who to invite. Providers were asked to personalize the invitations and also include a letter of encouragement from their agency. This letter of encouragement alleviated participants' concerns about how their contact information was used and accessed.

Managing the logistics of inviting participants was challenging because of the large number of focus groups conducted within a relatively short period of time. An additional challenge in mailing out invitation packets occurred when the participating agency administrators or staff were out of the office when materials arrived causing delays in sending out invitations to potential participants. These delays were further complicated by the unpredictable timing of the postal service. Regardless of these challenges, overall, each region had adequate participation in all focus groups (Map of Focus Groups and Personal Interviews Conducted, Appendix B).

Prior to individuals participating in a focus group, the contact information for each participant remained confidential and was only known by the individual inviting agencies. The time and location for each focus group or interview was detailed in the invitation letter and varied to fit the needs of that particular group. The invitation letter also informed consumer and family participants about the availability of stipends for focus groups and personal interviews. These stipends helped to reimburse individuals for their time, travel, and possible personal care attendant expenses. For focus groups conducted in the first two

regions, stipends of fifty dollars were given to consumer and family member participants. Considering the high number of initial participants and the grant's resources, the stipend amount was reduced to forty dollars for consumers and family members in the remaining regions. After potential focus group and in-home interview participants received the letter of invitation (Letter of Invitation See Appendix F) they were instructed to call or email the Real Choice Rebalancing Grant Project Director to give the appropriate contact information. Despite the request for participants to contact the project director prior to each focus group, participants would often arrive unannounced at the focus group rather than calling ahead.

Before beginning each focus group the facilitator took time to personally meet each participant. In addition, at the beginning of each focus group, participants were asked to introduce themselves and share a brief overview of why they were there. These two approaches allowed the facilitator to know who was part of each group and served as a method to screen the participants. If the facilitator became aware that a potential participant did not fit the criteria for that particular focus group, the facilitator would talk to the individual privately. The facilitator would explain the need to make sure everyone fit the criteria so that all participants felt comfortable to openly express their views. These individuals were reminded of the importance of participant confidentiality, and then asked to excuse themselves. This situation occurred several times when providers of continuum of care or family members wanted to observe the focus group rather than participate. The focus group facilitator made every effort to screen outside observers in order to protect the privacy of participants and preserve the validity and the candor of the information gathered.

### *Initial Studies and Field Trials*

Initial planning for this research involved input from the Real Choice Rebalancing planning and steering committees, including both consumers and providers of continuum of care services. Their feedback was used to develop and refine the focus group and personal interview questions. An initial pilot focus group was conducted with consumers of home and community based services in North Dakota prior to implementing the study statewide. The initial script and questions field tested with this initial focus group are included. (See Appendix I) Adaptations to the focus group plan were made as necessary after the test was completed. Adaptations included streamlining and making accessibility accommodations in the paperwork process to allow more time for the focus group discussions.

### *Voluntary Participation and Informed Consent*

At each focus group and personal interview, all participants were provided with a short description of the study outlining its goals and activities. All participants in the various focus groups and personal interviews were informed that participation in the study was voluntary and that they could withdraw at any time by notifying the RCR project principal investigator, the inviter, or MSU's Institutional Review Board Chair. They were made aware that if they decided to withdraw from the study it would not affect their eligibility to receive services.

Informed consent was also obtained from the consumers, family members and providers participating in the study. The informed consent (Voluntary Participation and Consent Form , Appendix G) included a brief description of the study, description of focus

group or personal interview process, data collection tools, reporting process, the intended use of the data, and a participant's bill of rights. (Participant's Bill of Rights, Appendix H)

Participants were informed that they may add, delete, or change any of their information during the study.

### *Data Collection and Analysis*

*Focus Groups.* A total of thirty-six focus groups were conducted. (See Map of Focus Groups and Personal Interviews Conducted, Appendix B for locations and numbers of participants.) The details regarding the process, script, and questions for focus groups and the personal interviews are explained in the detailed focus group and personal interview plans (See Appendix I).

Data collection instruments at each focus group included an audio recording and facilitator and assistant notes. A thank you letter and summary of the information gathered was sent to all participants for their review. Each focus group recording was transcribed into a text document, omitting participant names from the transcripts. Once the transcription was complete, the information was entered into a qualitative data analyzer, *Ethnograph*, Version 5.08, from Qualis Research distributed by SCOLARI. This computer software was then used by the Principal Investigator, with the help of the project assistant, to organize, categorize, and code the patterns and themes of the data collected. Data were then analyzed to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access to long term care supports, (i.e. home and community based

services and nursing home care) for the elderly and persons with disabilities. As part of the data analysis, a validity check was also conducted by having a second person conduct the cross check analysis of a random selection of focus groups.

*Personal Interviews.* A total of seven personal interviews were conducted throughout the eight human service regions in both rural and urban communities of North Dakota. A regional map of both the focus groups and personal interviews conducted and the number of participants for each region is included in Appendix B. Participants for personal interviews were invited in the same way as focus group participants. When the participant was invited to a focus group the provider could discuss with them the possibility of a personal interview when travel to a focus group was not possible. When an invited participant preferred a personal interview, he/she would then contact the project director to set up the interview date, time, and location. These procedures ensured that privacy and HIPAA standards were upheld.

Similar data gathering and recording methods were used to gather information through personal interviews. On one occasion when travel by the consumer and project staff was not possible, a personal interview was conducted by telephone. Interviews were conducted with consumers of home and community based services, elderly nursing home residents, younger nursing home residents and/or family members when it was difficult to gather through focus group participation. The same script, questions and data collection procedures were used in the focus groups and personnel interviews. The same procedures in accurate recording and confidentiality were also followed with this group. These data also help describe the impact the continuum of care services in North Dakota have on elderly and people with disabilities.

## **Focus Group and Personal Interview Results**

The extensive focus group and personal interview process gathered a rich set of information and the results reflect the common needs and concerns expressed by the participants.

### *Common Cross-Group Themes Expressed by North Dakotans*

The cross-group themes identified include the common patterns that have emerged across all five types of focus groups conducted. These common themes have been organized into the following three broad categories:

- how North Dakotans currently find out about continuum of care services,
- common problems regarding continuum of care services, and
- common needs regarding continuum of care services.

### *North Dakotans currently find out about continuum of care services through:*

- Social workers: These included hospital, nursing home and county social workers.  
Participants did not always indicate the type of social worker that was providing information and at times it was more than one.
- Doctors and hospital staff
- Word of mouth: This is information shared very informally through friends, neighbors, and others who may have used a service, and by chance.
- On their own
- Family members

Quotations from focus group and personal interview participants included:

"I had a nurse that told me to talk to social services." Consumer of HCBS

"Had it not been for maybe some neighbors of mine that used some of the services, I would have never known that they existed." Family member

"I find out about it more by word of mouth than anything else [and] by people that have used those services." Family member

"I didn't have a choice, my mom and sister decided that I should come here." Younger nursing home resident

"You know you start talking to friends and looking in the phone book and trying to figure it out." Younger nursing home resident

"At age 18 I had to do it [find services] on my own." Consumer of HCBS

"Where are you going to go, the first person I am going to see is either going to be my doctor or it may be a church, but it's probably not going to be some government office." (Family member)

How individuals indicated that they are finding out about continuum of care services is important because it shows that North Dakotans are not consistently finding this information in one place. The various means show that the current system for accessing services is neither streamlined nor easily understood. These issues are also reflected in the common problems related to continuum of care services that emerged from the data.

*Common problems identified regarding continuum of care services include:*

- Confusion of the information that people receive
- High cost of services, both nursing home and home and community based services, is a barrier to receiving those services
- Lack of information about continuum of care services that are available in the community, lack of quality, comprehensive information,
- No choices available for continuum of care services in the community

- Lack of flexible funding to support consumer's choice of continuum of care services

Quotations from focus group and personal interview participants included:

"Some of those requirements are different from one agency to another. One place they count your cars or assets or income, and the other place they don't, here you can have a burial account, there it counts against you. So ... nobody tells you the rules of this game." Family member

"Then you ask a doctor and they're so confused [he] will say 'I don't know, they change the system so much I don't know what you can and can't get anymore.' He's so mind boggled by the whole thing so he doesn't even know what to say. Any they're so boggled by the paper work that they're so confused." Family member

"It would be helpful if there were someone there that would tell you rather than send you on again because that happens so often too. You get to one place and then you go there and then you have to go over there." Elderly nursing home resident

"There are good, qualified, trained people, who are very helpful; unfortunately most of us don't even know where they are." Family member

"I took care of my wife for 16 months and at that time I had to do everything, I did all the cooking, cleaning, all of the wash, dressed her, cleaned her up, took her to her appointments and I didn't know where to turn I didn't know where I could get some help." Family member

"Even though I have been working with a social worker, I didn't even know until tonight that the senior centers even have home health care, I didn't know about dial-a-ride until tonight. So it is helpful." Family member

"My mother would be home right now if I could afford the \$8/hour for someone to watch her. But yet I couldn't get the funding to keep her at home. Because [Medicaid] will pay to put her in a nursing home but they won't pay to keep her at home, when it would not cost them nearly as much." Family member

"Social services is so busy that you can't even get in there... you wait two hours to get to your appointment and you get 5 minutes. And you see a social worker and boom you're done, that's it. And most of the time you don't even know who they refer you to...it's just like you left the way you felt when you went down there, you're in and out and boom." Younger nursing home resident

"I very much feel like I am trying to stick a square peg in a round hole [when trying to coordinate services for the elderly] and if the person does not fit these criteria there is no possibility, and I think that is one of the big contributors [in] having to choose different options for life and there is simply not [any choice] because they don't fit this peg but they fit in this peg and so they need to move over here." Provider

"There are very limited choices for the Medicaid recipient. Many of the phone calls that I receive I'm quick to get to the funding piece of it. And yet you know, hopefully people understand why because your options are based on your finances. And there's many, many, many more choices for the person with the financial resources." Provider

*Other common problems identified include:*

- Living in a rural community, isolated from services that are not available in the community
- No needed services available or not enough workers available to provide the needed HCBS
- Not eligible for needed services

Quotations from focus group and personal interview participants included:

"Someday I will have to reside in a nursing home because I won't be able to find someone or won't be able to pay for them." Rural Consumer of HCBS

"Trying to find anyone to help with the shower ... there isn't many of [them]." Younger nursing home resident

"I had a nurse tell me to talk to social services but the only thing that I got help with is washing my clothes...but I'm just a few dollars over that I can't get help with anything else that I could have used." Consumer of HCBS

*Common needs identified regarding continuum of care service:*

- case management described as assistance with assessment, care planning, provider selection, monitoring services, and making referrals
- both functional and financial assessment
- a reliable, consistent, and knowledgeable “go to” person, this person should have access to necessary resources
- a single point of entry system for streamlined access to services; a simplified service system
- access to comprehensive, timely information about services
- home and community based service options including access to HCBS in rural communities
- public education and media related to available continuum of care services and preventative education
- flexible funding to pay for the service of choice
- alternative housing options

Quotations from focus group and personal interview participants included:

“You’d be surprised what little bit of care you could get in your home would make your life [easier], so much as an hour a day makes such a difference. I have three hours of help during the week and it just means the world to me.” Family caregiver

“I want [ed] one voice that was nice and that would give me the same answer twice to the same questions and know what they were talking about.” Family member

"You need to have a multi-faceted evaluation. It would probably take more than one person." Family member

"They [case management] need to be knowledgeable about what's out there so that they can give you the appropriate information in a great timely manner and say, okay you have this option, this option, [and] this option." Consumer of HCBS

"We need a place where we can find the services that the person needs, preferably a handicapped person [to help us] who knows about all these things... They [case managers and consumers] need a place that you can sit down and talk and show them [case managers] what you've got and they have a look at your house and see if there are any problems with it, fix your house and find out what's right for you." Younger nursing home resident

"If you look at how health care is delivered today,...it is driven by payment systems rather than for assessment with goals for patient management...and so what are we doing, we aren't taking care of patients, we are doing assessments for billing...When you step back, man this thing is broken. We are all doing our own thing and nobody is communicating." Provider

"I often get calls from physicians that seem frustrated with the system or the process now that it's not as easy as it used to be." Provider

"My sister has a year old baby and she has someone who comes every so often and it's a free service and they assess the baby, how she is doing. But really that's what our older people need. They need someone coming in that same type of mode whether they need it or not and then educating them. Now do you have nursing home insurance? Do you have this, are you thinking about this coming up? You know this is what you might need to do. How we could get those people to accept someone to come into their home. That is what we need." Provider

"Because these are emotional questions to start with and then when you add the time factor, the stress factor, the frustration, you need somebody you feel like you can trust to help guide you through the insanity. Because you just don't know where to go. And it's not that people weren't nice but sometimes you can't get back to them." Family member

"Assisted or self assisted living, I think Medicare [Medicaid] should help pay for things to keep you in the home instead of the nursing home and expenses would be a lot less. And at home it's better I think." Younger nursing home resident

"I'd love to be at home but the shots that I get for my MS are so expensive, in here [nursing home] I get them for free. I have a house; I'd rather be at home. I have...

[children]...still living at home.” Younger nursing home resident

*When participants were asked to express their thoughts about paying for needed services the following themes emerged:*

- Individuals expressed willingness to privately pay for the services needed for as long as possible, however it is necessary to provide advice, choice and information about cost of services to assist people in making appropriate financial choices.
- Participants expressed frustration with not qualifying for Medicaid or other state funded help to pay for needed and chosen services especially when their personal resources were very limited.
- Some participants also expressed frustration with misinformation and lack of understanding about payment systems including: long-term care insurance policies, private insurance, Medicare and Medicaid.
- It was also expressed by some the understanding that the “state” was paying for their services.
- Some participants wanted to be able to save some money to pass on to family members.
- Family members expressed that they often help with paying for needed services but to pay a significant amount is burdensome to the family and their future financial needs.

The majority of focus group participants were either currently paying for services

privately or through Medicaid. There were very few who were using private insurance or long term care types of insurance to pay. This is consistent with a lack of information available including lack of information about long term care insurance and a lack of understanding of the current payment system.

Quotations from focus group and personal interview participants included:

"I suppose I would like the other fellow to pay for some of it and all...but within reason you do [pay for] what you feel you are able to deal with at the time."  
Consumer of HCBS

"Most of us are over 80 and it occurs to you that you might run out of money so you need help." Elderly nursing home resident

"Well if you can't afford it [privately paying], it's [state funded assistance] good I suppose because it costs a lot of money to stay in these places and get a lot of care."  
Elderly nursing home resident

"We got all that [equipment] free and I don't know whether it was because she's on Medical Assistance, or on Medicaid or on Medical Assistance because of her age." Family member

"His grandmother lost all her money to the nursing home because that didn't switch it over. But then you are deceiving the government by switching it all over. But then why did you work your whole life to pay for a nursing home?" Family member

*A Simplified System of Services.* A common theme identified was the need for a simplified system of services or a single point of entry system to improve access to services. Participants were asked the following question: If you were able to go to one place to find out about all of the available services in your community please describe what it would be like? This question brought out participants' suggestions for what would be useful for them to simplify access and use continuum of care services. This

question helped to identify what individuals would want a single point of entry to be like or where they would want it to be. In addition to the already mentioned themes that emerged, participants had a wide variety of thoughts regarding the single point of entry concept. These additional suggestions were not part of a theme that emerged but instead were unique to each participant and suggested the need for a streamlined system of services. For report purposes the term single point of entry (SPE) will be used to include those thoughts that were expressed to answer the above question.

*Thoughts expressed included ideas for **where** a SPE should be located or **who** should provide the SPE services.* A common cross-group theme identified was that a necessary component of a SPE must be a reliable, consistent, and knowledgeable “go to” person. Another common cross-group theme identified was that it is necessary for a SPE to be locally available, with in reason, to consumers and family members.

“A real person [is necessary], I think elderly population especially, I know I finally did resort to a flat screen for my desk at work, but for years I felt like...there’s computers up and down the hallway in every office. And I just didn’t want to project that image to people that were coming in for help.” Provider

*The following additional suggestions, not part of a theme that emerged, were unique to each participant and suggested the need for a streamlined system of services.*

- *Ideas from Consumers of HCBS*

Human service center, center for independent living, brochures, social workers, court house in each county seat, hospitals, 800 number, close to home, post office, each town, newspaper, social services

- *Ideas from Elderly nursing home residents*

Central place, nursing home social workers, part of nursing home, senior center, social services, doctor's office, list in the telephone book, chamber of commerce, hospitals

- *Ideas from Younger nursing home residents*

Center for independent living, human service centers, social services, come into the home

- *Ideas from Family members*

Large medical facility, senior center, social service center, central locations with office spaces in rural communities, doctors,

- *Ideas from Providers*

Central location for information about all the options for any income level, public health, nursing homes, 800 number, website, interview offices where people are trained to do the assessment, applications and eligibility ..., streamlined computer system for providers to access all services, outreach workers, one office to limit need to travel from office to office, set up a "health center or a life center," county social services, nursing homes.

Quotations from focus group and personal interview participants included:

"I think it would be good to have a central office where... you could find out about everything at the same place." Consumer of HCBS

"If they would list the place[s] in the telephone book." Elderly nursing home resident

"What I'd like to see is kind of a cities' human service centers put something out there ... where you can ... cover the region." Younger nursing home resident

"You almost need travel, people that could come to these small [communities] sometimes and spend a day or so people could make appointments [with that person]." Family member

*Thoughts expressed by each group also identified the following types of services a SPE*

*should include.* Case management, assessment, a go-to person, information about equipment, information about services available, long term care and private insurance information, home repair and maintenance information, information about how to make a home accessible, where to find accessible housing, information about alternative housing, lists of various workers, respite care information, the cost of services, transportation, information about the payment system, eligibility criteria for various programs.

*Access and choice to all groups.* A common theme that emerged was a need to offer access and choices in continuum of care services to all groups including what some call the middle income group, any group that may not qualify for Medicaid or other programs based on income, those who are not wealthy enough to privately pay for needed services for any significant length of time, and people covered under workers compensation.

Quotations from focus group and personal interview participants included:

“Well to hell with them, it doesn’t do me any good. Nobody in all of social services can help me at all because I’m covered by workers comp.” Consumer of HCBS

“I can’t get on any help like that through the county because my income is too high. But mine is just on the line where it is too high for the services, and not high enough to do it all [pay for services]. It’s a hard place to be. It’s not a good place to be.” Consumer of HCBS

### *Common Themes Expressed by Individual Groups*

*How North Dakotans currently find out about continuum of care services:*

- *In the **provider** focus groups the common theme emerged that consumers often find out about continuum of care services through referrals from various continuum of care providers.*

This theme was unique to the provider focus groups and did not emerge from the other focus group participants. This suggests that providers of continuum of care services and those who use those services have different perspectives about how well the current information and referral systems work at connecting consumers to services.

*Common problems regarding continuum of care service:*

- *A common problem identified by both **family members** and **providers** regarding continuum of care services was the need for help in crisis situations.*

Quotation from focus group and personal interview participants included:

“Today I ended up having two hours to make a decision. Eleven o’clock they called and told me, oh the nursing home that you’re looking at putting her into wants too much money; they want a front of \$6200. It’s like, she don’t have that, and I don’t have that money to dish out of my pocket... there’s no way I can afford to do that every month for her. So we had to hunt around and I am going to have to start putting her on MA [Medical Assistance] and everything just came in and fell all in my lap and had by 1:30 pm to make all the decisions. Decide where she is going, how it’s going to be financed, everything. And get it all rolling so that she can move out of the hospital by three o’clock. Yeah, it’s not fun, very stressful.” Family member

- ***Consumers of HCBS** and **providers** indicated lack of accessible transportation or any transportation at all as a problem that affects access to continuum of care services.*

Quotation from focus group and personal interview participants include:

“I need help with transportation because I don’t drive a car, and my children live out in the country quite far away. And that’s what [I] most long for help [with].” Consumer of HCBS

- *A common **problem** emerged from **family members** that being the family home*

*caregiver can be a burden and often stressful. This also identifies a need for continued and further support for family caregivers.*

- *Consumers of HCBS, younger nursing home residents and families indicated that a lack of appropriate HCBS hours for the circumstances was a problem. This included a lack of flexible hours beyond 8am to 5pm and needed access to 24 hour home care services.*
- *Common problems that emerged from families and providers included low pay for qualified services providers (QSPs).*
- *Providers indicated that an out of town families' distance from consumers can be a problem when coordinating continuum of care services.*

Quotation from focus group and personal interview participants included:

*"I guess I feel frustrated at times because most often you want people to have services in their homes yet you also want to stay open for the people we're providing a full census to operate." Provider*

- *A common problem that emerged from elderly nursing home residents was that even if they wanted to leave the nursing home after a time and return to the community, residents often had no home left and /or no household items left and felt it was too burdensome to start over. This was expressed as a barrier to returning to the community.*

Quotations from focus group and personal interview participants include:

*"I would be ready to move back to [ ] any day if I had my furniture, but everything is cleaned out, but I enjoy it over there and I enjoy it over here too...everything is gone." Elderly nursing home resident*

“I would be at home if I could but my kids put me in here and shut up my house, turned off the water and power, so I can’t go back in otherwise I think I would.” Elderly nursing home resident.

- *Families indicated that the complicated and tedious QSP paper work was a problem and a barrier to providing HCBS.*
- *A common problem that emerged from the **elderly nursing home** and **provider** groups was that before entering the nursing home, consumers were sometimes too proud or afraid to ask for help, such as home and community based services. This became a problem when consumers waited too long and their conditions worsened necessitating nursing home level of care.*

Quotations from focus group and personal interview participants include:

“I think [we] are too proud to ask for help, that’s how we were brought up here in North Dakota.” Elderly nursing home resident

“I knew there were several things available but it never crossed my mind, you know we just don’t ask.” Elderly nursing home resident

- ***Providers** indicated that to some consumers there may be a negative stigma about going to county social service offices and/or about Medicaid because of association with “welfare.” This was thought of as a problem or barrier to accessing continuum of care services.*

*Common needs regarding continuum of care services*

- **HCBS consumers** and **families** indicated a need for respect and compassion when dealing with various agencies to coordinate services.

Quotation from focus group and personal interview participants included:

“I always feel like my whole family is in the military, we served the country. You

know, I wish... I could use that to say hey could we just get a place in Bismarck for me. Maybe I shouldn't use it like that but darn I feel like I'm just thrown over here and forgotten about or whatever." Younger nursing home resident

- *The need for communication throughout the continuum of care process was a common theme that emerged in the **family** focus groups.*
- *A common theme that emerged from **elderly nursing home residents** indicated that they were content with their current continuum of care services. These thoughts included being content and happy with the services provided by the nursing home. This contentedness with living in the nursing home was also described as developing over time. Some participants' contentedness with living in the nursing home developed over time because it was often the only choice available for various reasons including: lack of HCBS services, level of care needed, or it was the affordable option because of Medicaid payments.*

Some elderly residents also indicated that they would like to live at home if the necessary supports were available.

- ***Consumers of HCBS and younger nursing home residents** expressed the need for home maintenance and repair services and workers available to assist consumers with household upkeep needed in order to make it easier for them to live in their own homes.*

Quotation from focus group and personal interview participants included:

"someone to help with maintenance when I can't do something around the house...cause sometimes we forget about those things, we just think about personal type things." Consumer of HCBS

- ***Consumers of HCBS** indicated a need for easy access to accurate and up-to-date lists*

*of various HCBS workers.*

- ***Younger nursing home residents*** indicated a need for medication assistance and management. This was reflective of a lack of HCBS medication assistance that was sometimes a factor in nursing home placement.
- ***Consumers of HCBS and families*** expressed the need for respect and compassion when working with providers and dealing with coordination of continuum of care services.
- ***Families*** expressed a need for respite care services.

Quotation from focus group and personal interview participants included:

“Caregivers have a whole range of emotions...there isn’t one thing that has escaped us...from depression, anger and sleeplessness. The thing is with a caregiver that you have to remember is that person is in your home; it is seven days a week, 24 hours, there is no break.” Family member

*The following themes were identified from groups of participants expressing what is important to them.*

#### *Consumers of HCBS*

- Avoiding institutional care
- Maintain independence
- Less costly continuum of care service alternatives
- The opportunity to stay at home

#### *Elderly nursing home residents*

- The opportunity to stay at home
- The opportunity to live with or near family

*Younger nursing home residents*

- Maintain independence
- The opportunity to live with or near family
- The opportunity to stay at home

*Family members*

- Avoiding institutional care

*Providers*

- Avoiding institutional care and maintain independence
- The opportunity to live with or near family

Quotations from focus group and personal interview participants included:

“None of us asked to be this way but we can’t help it. And if we can live cheaper at home and be a lot happier at home it all makes sense.” Consumer of HCBS

“I just want to keep her out of the nursing home.” Family member

“If there is somebody who needs care in their own home that can be provided...that person can remain in their own home rather than going to a higher level of care such as a nursing home.” Provider

“Truthfully there is a time for the nursing home and they are very grateful...to access that. I think we could delay that longer and in terms of paying for it [nursing home care]; I think we have seen as much money as we’re going to see out there.” Provider

## **Conclusions/Recommendations**

Based on the results of this research the following conclusions and recommendations have been identified:

1. The current 2005-2007 biennium funding for long term care services (i.e. continuum of care services) includes \$343,013,040 appropriated to nursing homes and \$37,697,922 appropriated to home and community based services. Since 1999, funding for nursing home services has increased by approximately \$90,600,000 while funding for HCBS has only increased by approximately \$16,700,000. This funding does not reflect the needs and preferences identified by the focus group participants for additional home and community based service options and the importance of the opportunity for consumers to remain in their own homes. It is important to note that data from all five groups (including providers) supports the desire of people to remain in their homes. There must be a concerted effort to implement change that will help to balance the funding for providing continuum of care services. Without such change, a certain crisis in providing care for North Dakota's growing population of aging citizens may occur.
2. In order to implement systems change in North Dakota, Medicaid and state funded services, the people using those services, and also those who are privately paying for continuum of care services need to be considered. This is necessary to build a proactive and fiscally responsible system that wisely spends and appropriately uses its funds for the services that North Dakotans prefer, and those services that are most effective at helping people maintain independence and self reliance.
3. There needs to be support and funding for pilot projects for a single point of entry (SPE)

concept, which can serve as an effective tool and step to improving choice and access to continuum of care services. The SPE projects should focus specifically upon the need for a consistent “go to” person, financial and functional assessment, case management type services, access to comprehensive timely information about services, access to increased HCBS options including access in rural communities, and availability to various income populations.

4. The shortage of workers available to provide continuum of care services and particularly home and community based services should be addressed. A system that will support and equitably reimburse providers of home and community based services, both individuals and agencies should be funded.
5. The need for unbiased functional and financial assessment and case management services should be addressed in order to ensure consumers have access to choices and services that are most appropriate to their needs. Exploration of how other states have used the idea of different levels of case management, such as options counselors and care coordinators, and streamlined assessment processes should occur.
6. Federal and state initiatives that allow flexible use of funds to pay for the services that consumers choose, such as Money Follows the Person, Cash and Counseling, home and community based services in the Medicaid State Plan, and items of the Deficit Reduction Act should be explored and implemented when appropriate.

## **Appendix A**

### ***Focus Group Regional Schedule***

## Real Choice Rebalancing

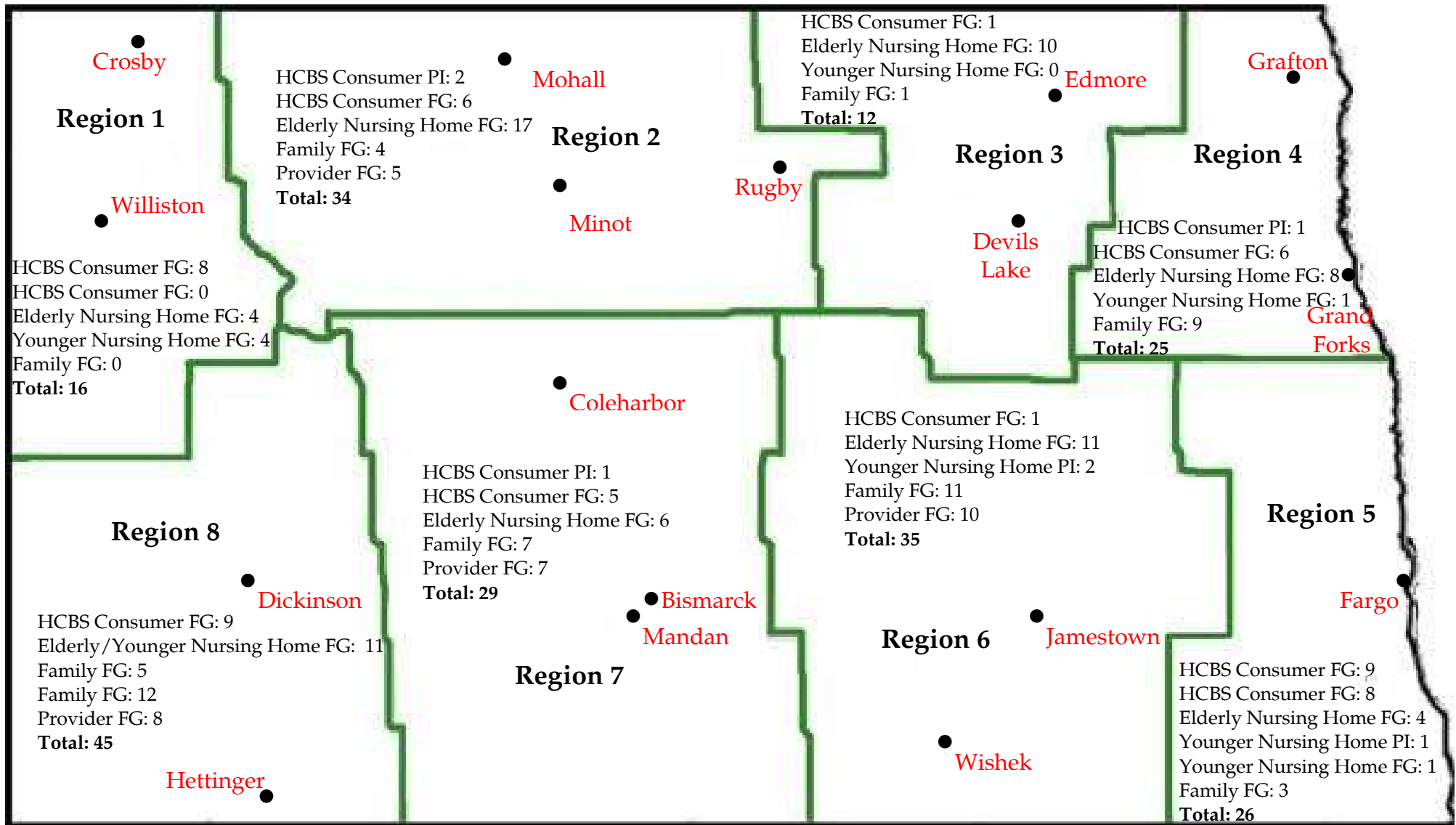
### *Weekly Schedule for Regional Focus Groups*

Week of Sept. 19 <sup>th</sup> , 2005	Fargo, Region 5- <i>Pilot Focus Group</i>
Week of Oct. 10 <sup>th</sup> , 2005	Dickinson, Region 8
Week of Oct. 17 <sup>th</sup> , 2005	Jamestown, Region 6
Week of Oct. 24 <sup>th</sup> , 2005	Bismarck, Region 7
Week of Nov. 1 <sup>st</sup> , 2005	Fargo, Region 5 <i>continued</i>
Week of Nov. 7 <sup>th</sup> , 2005	Grand Forks, Region 4
Week of Nov. 14 <sup>th</sup> , 2005	Minot, Region 2
Week of Nov. 28 <sup>th</sup> , 2005	Devils Lake, Region 3
Week of Dec. 5 <sup>th</sup> , 2005	Williston, Region 1
Week of Dec. 12 <sup>th</sup> , 2005	Bismarck, Region 7 <i>continued</i>

**Appendix B**

***Map of Focus Groups and  
Personal Interviews Conducted***

## Focus Groups (FG) and Personal Interviews (PI) Conducted Including Number of Participants



Total Focus Groups Conducted: 36  
Total Personal Interviews Conducted: 7  
Total Participants: 222

HCBS Consumer Participants: 57  
Elderly Nursing Home Participants: 71  
Younger Nursing Home Participants: 18

Family Members of Consumers of Continuum of  
Care Services Participants: 46  
Providers of Continuum of Care Services: 30

## **Appendix C**

### ***Participant Criteria***

## **Descriptions of Criteria for Real Choice Rebalancing Focus Group Participants**

*Please consider the following information as you invite potential focus group participants.*

### ***Group A - Consumers of Home and Community Based Services***

#### **Attributes of focus group participants:**

- Elderly and/or persons with disabilities who live in their homes or in a non-institutional setting, may include assisted living and private pay individuals
- Age: 21 years and older
- May include Individuals with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- Immediate family members or care givers may also be present based on the nature of a consumer's need for a personal attendant present
- Individuals with transportation to the meeting sight
- Preferably consumers not more than approximately 40 miles from meeting sight (suggestion)
- Based on volunteer participation

### ***Focus Group B - Elderly Nursing Home Residents***

#### **Attributes of focus group participants:**

- Elderly and/or persons with disabilities who currently reside in a nursing home
- Participants need to be cognitively intact and able to communicate with appropriate supports
- Age: 60 years and older
- Focus on those elderly who live in the nursing home, those who need personal care including ADLs and IADLs.
- Immediate family members or caregivers may also be present based on the nature of the situation and need for supports
- Focus Groups will be held in the nursing home if possible so transportation will not be an issue for most participants. When possible some participants will be asked to attend a focus group at another community nursing home.
- Based on volunteer participation

### ***Group C- Younger Nursing Home Residents with Disabilities and their Families***

#### **Attributes of focus group participants:**

- Persons with disabilities who currently reside in a nursing home
- Participants need to be cognitively intact and able to communicate with appropriate supports
- Age: 21 to 60 years old

- Focus on those with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- Immediate family members or caregivers may also be present based on the nature of the situation and need for supports
- Focus Groups will be held in the nursing home if possible so transportation will not be an issue for most participants. When possible some participants will be asked to attend a focus group at another community nursing home.
- Based on volunteer participation

***Group D - Family members who have been faced with a crisis situation when seeking continuum of care services for elderly or people with disabilities***

**Attributes of focus group participants:**

- Close family members who have been faced with a crisis situation when seeking continuum of care services for elderly or person with a disability
- Age: 21 years and older
- Focus on those who have been faced with a crisis situation. Focus on those who have family members with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- People who have transportation to the meeting sight
- Preferably participants not more than approximately 40 miles from the meeting sight (suggestion)

***Group E – Providers***

**Attributes of focus group participants:**

- Providers of continuum of care services
- Focus on those who refer or provide continuum of care services for adults with physical disabilities and long term illness, or elderly who need personal care including ADLs and IADLs
- People who have transportation to the meeting sight
- Preferably providers not more than approximately 40 miles from the meeting sight (suggestion)

**Appendix D**

***Steering Committee Membership***

<b>First</b>	<b>Last/ Alternate*</b>	<b>Agency</b>
Linda	Wurtz / Janis Cheney *	AARP North Dakota
Kathy	Hogan / DeLana Duffy-Aziz *	Cass County Social Services
Jane	Strommen	Community of Care Cass County
Rodger	Wetzel	Community Health and Eldercare, St. Alexius Medical Center
Mark	Kolling	Developmental Disabilities Division (DD)
Carol	Olson / Tove Mandigo *	Dept. of Human Services, Director
Linda	Wright / Robin Schumacher *	DHS, Aging Services Division
Maggie	Anderson	DHS, Medical Services Division
Karin	Mongeon*	DHS, Medical Services Division
JoAnne	Hoesel	DHS, Mental Health and Substance Abuse Division
Gordon	Hauge / Marilyn Bender *	Easter Seals Goodwill of ND
Chuck	Stebbins / Mark Bourdon*	Freedom Resource CIL / Consumer
Amy	Clark	Governor's Committee on Aging
Duane	Houdek	Legal Counsel to the Governor
Cheryl	Kulas	Indian Affairs Commission
Theresa	Snyder	DHS / Tribal Liaison & Program Civil Rights Officer
Marcia	Sjulstad / Jo Burdick *	ND Association for Home Care
Darleen	Bartz	ND Dept. of Health, Division of Health Facility
James	Moench	NDDAC
Shelly	Peterson	ND Long Term Care Assoc.
Kurt	Stoner*	ND Long Term Care Assoc./ Bethel Lutheran Home
Tom	Alexander	ND Medicaid Infrastructure Grant/NDCPD
Bonnie	Selzler	Olmstead
Bruce	Murry / Teresa Larsen *	Protection and Advocacy
Amy	Armstrong / Kylene Kraft	Real Choice Rebalancing Grant/NDCPD
MariDon	Sorum / Sandy Arends*	Regional Aging Services Program Admin. North Ctrl. Human Ser. Ctr.-
Sandy	Arends / MariDon Sorum*	Regional Aging Services Program Admin.- SE Human Service Center
Gary	Kreidt	Representative
Richard	Dever	Senator
Joan	Campbell	South Central Adult Services, Inc
Bob	Puyear	Consumer
Shauna	Barth	Family Caregiver

**Appendix E**  
***Inviter Agency Cover Letter***

October 27, 2005

«AddressBlock»

«GreetingLine»

As the project director, I am writing this letter on behalf of the *Real Choice Systems Change – Rebalancing Grant*. In September 2004, the North Dakota Department of Human Services – Aging Services Division was awarded the grant from the Centers for Medicare and Medicaid Services. Over the past several months the project has had several Planning and Steering Committee meetings and has researched and gathered studies and reports regarding continuum of care for elderly and people with disabilities in North Dakota and other states.

The next step in the grant is to conduct additional research to gather the information necessary to help us identify current perceptions and suggestions for the development of a mechanism for funding and a single point of entry for continuum of care services in North Dakota. One piece of this research will be conducting state wide Focus Groups.

This research will be conducted in various regions to include both rural and urban populations and will focus on these population areas:

- Consumers of Home and Community Based Service
- Elderly Nursing Home Residents
- Younger Nursing Home Residents with Disabilities and their Families
- Family members who have been faced with a crisis situation when seeking continuum of care services for elderly or people with disabilities
- Providers of continuum of care services

I would like your assistance in inviting participants to **Regional Focus Groups**. In addition to your help, we have also randomly invited other agencies in your region for assistance with these mailings. Our goal is to have approximately 10-12 participants at each Focus Group. I anticipate each Focus Group to last an hour and a half. Stipends will be available to consumer, nursing home resident, and family member participants and light snacks will be provided.

I would like you to invite individuals to participate in these Focus Groups. *More details are included in this mailing regarding what type of focus group, specific times and locations.*

To assure that confidentiality and HIPPA standards are upheld, I have enclosed invitation letters and envelopes for you to send to these potential focus group participants. *You have been given a specified number of invitations and envelopes and one extra invitation for possible printing errors.* I would like each invitation addressed to the participant to make the letter more personalized. I have included instructions on how to personalize each letter. I would also like to encourage you to enclose a personal note of encouragement. This will assure the participant that you and your agency were the connection in making sure that they received a personal invitation and all privacy considerations were upheld.

Participants are asked to directly contact Real Choice Rebalancing project staff if they are interested in participating. I ask that you not hesitate in mailing out these invitations. Please contact me if you have any questions.

An additional note, if you are considering inviting a potential focus group participant but realize that travel may be a barrier, please consider this person for a *personal in-home interview*. Please contact me if you would like to discuss a possible personal in-home interview. *If an individual is interested in a personal in-home interview, please discuss this with them and have the individual contact me.*

Thank you in advance for your collaboration!

Sincerely,

Amy Armstrong  
Project Director  
North Dakota Real Choice Rebalancing Grant  
Phone: 1-800-233-1737  
Email: [amy.armstrong@minotstateu.edu](mailto:amy.armstrong@minotstateu.edu)

Enclosed:

Invitation letters

Stamped envelopes

Sample courtesy letter from your agency to include with invitation letter

Instructions for personalizing invitation letters

*Real Choice Rebalancing Project Brochure*

**Appendix F**  
***Participant Letter of Invitation***

Date

Address

Dear ,

In September 2004, the North Dakota Department of Human Services – Aging Services Division was awarded a *Real Choice Systems Change – Rebalancing Grant*, called “Choice and Self-Directed Community Resource Delivery for the Elderly and People with Disabilities in North Dakota.” This grant is taking an in-depth look at services for the elderly and people with disabilities. We are considering ways to make it easier for you to stay independent as you age.

As the project director for the North Dakota Real Choice Rebalancing Grant, I would like to invite you to participate in a very important focus group in your region. You have been asked to participate in this focus group because you have important thoughts and views that we would like to hear. At this focus group you will be able to express your thoughts on issues regarding choice and access to continuum of care services, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

We need your input to help us develop a plan for future resources and access to continuum of care services. The information that you share will also be shared with state officials, policy makers, legislators, and the governor to help ND develop a plan for a system that addresses your needs. The information gathered at the focus group will remain confidential and your privacy will be protected at all times. If you choose to participate you will also receive a summary of the information gathered.

The Real Choice Rebalancing **Consumers of Home and Community Based Services Focus Group** that you are invited to will be held on Wednesday, \_\_\_\_\_ 2005 from 2:00 pm to 4:00 pm at the \_\_\_\_\_ Public Library. A light snack will be provided and you will also receive a stipend for your time.

If you are interested in participating or have questions about this regional **Consumers of Home and Community Based Services Focus Group** on Wednesday, \_\_\_\_\_ 2005 from 2:00 pm to 4:00 pm at the \_\_\_\_\_ Public Library \_\_\_\_\_ please contact me, Amy Armstrong, the Project Director by calling 1-800-233-1737 or by emailing me at: [amy.armstrong@minotstateu.edu](mailto:amy.armstrong@minotstateu.edu).

Please respond by Tuesday, \_\_\_\_\_ 2005 if you are interested in participating in this important event. I look forward to meeting you!

Sincerely,

Amy Armstrong  
*Project Director*  
*North Dakota Real Choice Rebalancing Grant*

This information is available in alternative formats upon request.  
1-800-233-1737

**Appendix G**

***Voluntary Participation and  
Consent Form***

North Dakota Center for Persons with Disabilities  
Minot State University  
North Dakota Real Choice Systems Change Grant - Rebalancing Initiative  
*Choice and Self-Directed Community Resource Delivery for the Elderly and People with  
Disabilities in North Dakota*  
Research Study

Informed Consent Form

Sign both copies and keep one.  
Return the other copy to the Real Choice Rebalancing Project Office

Refer any questions to: Ms. Amy Armstrong, Project Director (800) 233-1737 or  
Dr. Margi Coxwell, Institutional Review Board Chair  
Minot State University (701) 858-3125.

Name of Participant: \_\_\_\_\_

Purpose of Study:

The North Dakota Real Choice Rebalancing (RCR) Grant is taking an in-depth look at the continuum of care system in North Dakota. The project will result in a plan for rebalancing funding resources and developing a statewide mechanism for single point of entry to continuum of care services in North Dakota for the elderly and people with disabilities. Your participation will help us discover what is working when accessing continuum of care services and what needs further change.

The goal of this research study is to conduct a series of statewide focus groups, in-home interviews, and questionnaires to discuss and identify current perceptions and suggestions for improving the choice and self-direction, quality and access of all long-term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities. This research will also be conducted to identify elements for the design of a single point of entry system for all long term care supports for the elderly and persons with disabilities in North Dakota.

Your participation in this project may help us to plan and develop balanced funding resources and a statewide single point of entry for continuum of care services.

Subjects:

Participants involved in the *Choice and Self-Directed Community Resource Delivery for the Elderly and People with Disabilities* research study will include the elderly, people with disabilities, and providers of the continuum of care services. This research project will also involve Real Choice Rebalancing project Planning and Steering Committees members along with the researchers at Minot State University.

I understand that participation in the project study is voluntary and that it may involve participating in a focus group or personal interview. I understand that information and data collected during this process will be used as part of the research and that I will be given the opportunity to give written or oral evaluation of the focus group and/or interview process.

Cost/Compensation:

I understand that there is no cost to me or my family for participating in the project's study. *I may receive a stipend for my participation. (This sentence will be deleted for the provider focus group participants.)*

Confidentiality:

I understand that all information obtained in this study will be kept confidential. I understand that this information will not be made available to anyone except those authorized to review the data collected.

All personal contact information will be kept on password-protected computer systems and in locked filing cabinets. Any discarded information will be shredded. I understand that any information obtained from this research project that personally identifies me will not be voluntarily released or disclosed by the researchers without my separate consent except as specifically required by law.

Participatory Research:

I understand that I am an active participant in this study and that my opinion and ideas are important to the researchers. If I have concerns or questions about the study or how I am being treated I can call Ms. Amy Armstrong (Principal Investigator) at (800) 233-1737. I can also talk to any of the project staff about my concerns.

I understand that participation in the study is voluntary and that I may withdraw at any time by notifying the project principal investigator, or Margi Coxwell at MSU. Deciding to withdraw from the study will not affect my eligibility to receive services that I am otherwise entitled to.

This study has been reviewed by the Minot State University Institutional Review Board and was approved. If you have any questions about the rights of human research subjects, please contact, Dr. Margi Coxwell, Chair of the MSU Institutional Review Board, at (701) 858-3125.

I have received a copy of the Experimental Subjects' Bill of Rights associated with the Real Choice Rebalancing project. I have been given the opportunity to review these materials and ask questions about the study. These questions have been answered to my satisfaction. I understand that any questions I may have about this research in the future may be answered by the Principal Investigator or a research study staff member.

My signature below indicates that I have read the information in this consent form and have been given the opportunity to ask any questions I have about the study. I consent to participate in this study.

_____ Signature of Participant	_____ Date	_____ Participant's Name (print)
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_____ Signature of Witness	_____ Date	_____ Witness Name (print)
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For Participants who are not legally responsible:

_____ Signature of Participant	_____ Date	_____ Participant's Name (print)
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_____ Signature of Guardian (or legally authorized representative)	_____ Date	_____ Guardian's Name (print)
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_____ Signature of Investigator	_____ Date	<u>Ms. Amy B. Armstrong</u> Principal Investigator
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**Appendix H**

***Participant's Bill of Rights***

North Dakota Center for Persons with Disabilities  
Minot State University  
North Dakota Real Choice Systems Change Grant - Rebalancing Initiative  
*Choice and Self-Directed Community Resource Delivery for the Elderly and People with  
Disabilities in North Dakota*

*Research Subjects' Bill of Rights*

Anyone asked to consent to participate as a human subject in a health services study or who is asked to consent on behalf of another, has the following rights:

To be told what the study is trying to find out.

To be told what will happen in the study and whether any of the procedures, therapies, services, or treatments is different from what would be used in standard service settings.

To be told about the risks, side effects, or discomforts which may be expected.

To be told if any benefit can be expected from participating and if so, what the benefit might be.

To be told of other choices available and how they may be better or worse than being in the study.

To be allowed to ask any questions concerning the study, both before agreeing to be involved and anytime during the course of the study.

To be told of any medical treatment available if complications arise.

To refuse to participate at all, either before or after the study has started. This decision will not affect any right to receive standard therapy or treatment.

To receive signed and dated copies of all consent documents.

To be informed when information that personally identifies me as a participant in this study is released to those who are not involved in my therapy, treatment, or services.

To be allowed time to consent or not to consent without any pressure being brought by the investigators or others.

_____ Signature of Participant	_____ Date	_____ Participant's Name (print)
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_____ Signature of Witness	_____ Date	_____ Witness Name (print)
-------------------------------	---------------	-------------------------------

For Participants who are not legally responsible:

_____ Signature of Participant	_____ Date	_____ Participant's Name (print)
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_____ Signature of Guardian (or legally authorized representative)	_____ Date	_____ Guardian's Name (print)
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_____ Signature of Investigator	_____ Date	<u>Ms. Amy B. Armstrong</u> Principal Investigator
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## **Appendix I**

### ***Focus Group and Personal Interview***

#### ***Script and Questions***

- A. Consumers of Home and Community Based Services
- B. Elderly Nursing Home Residents
- C. Younger Nursing Home Residents with Disabilities and their Families
- D. Family members of Consumers of Continuum of Care Services
- E. Providers

***Real Choice Rebalancing Grant: Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota***

**Focus Group / Personal Interview A - Consumers of Home and Community Based Services**

**Purpose Statement:**

to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities.

**Participants:** *Group A - Consumers of Home and Community Based Services*

**General information:**

- Number of Focus Groups: up to 8
- Various regions of North Dakota will be chosen for focus group sites including both rural and urban populations.
- Number at each meeting: up to 10
- Number to invite to each meeting: 20
- Total number of potential Consumers of Home and Community Based Services invited: 160

**Attributes of focus group participants:**

- Elderly and/or persons with disabilities who live in their homes or in a non-institutional setting, may include assisted living and private pay individuals
- Age: 21 years and older
- Individuals with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- Immediate family members or care givers may also be present based on the nature of a consumers need for an attendant present
- Individuals with transportation to the meeting sight
- Preferably consumers not more than approximately 40 miles from the meeting sight
- Based on volunteer participation

**Possible sources of invitations:** Various agencies will be contacted to assist with mailing invitations to the selected group. These agencies include: Centers for Independent Living, County and State lists of persons receiving services, Older Americans Act Service Providers, Regional Aging Service Program Administrators (RASPAs), Home Health Care Association, who are members of the *Real Choice Rebalancing* Steering Committee.

These agencies will be given a letter of invitation from NDCPD at Minot State University. The agencies will be responsible for mailing these letters to participants. This will assure that confidentiality and HIPPA standards are upheld.

Stipends will be available for focus group and personal interview participants.

Snacks will be provided.

### **Script, Questions, and Facilitator Instructions**

#### Arrival: (15 – 30 minutes prior to focus group start time)

Facilitator and assistant will greet invitees and help participants sign in when they arrive and verify their contact information. Participants will also be asked to fill out a W-9 Form and a *Real Choice Rebalancing* Stipend Form to receive their stipends.

#### The Opening: (15 minutes)

- Facilitator welcomes group and thanks them for coming, then introduces herself and the project assistant and explains the purpose of the focus group.
- Participants introduce themselves to the rest of the group.
- Facilitator presents the agenda for the session.
- Reminder of confidentiality of the information.

#### ***Script:***

*Hi, my name is \_\_\_\_\_.*

*Welcome to the focus group for the Real Choice Rebalancing project and thank you for joining us. I will be facilitating the focus group today. \_\_\_\_\_ will be serving as a recorder for the focus group in order to record your information accurately.*

*As was detailed in your invitation letter this is one of a series of focus groups that are being conducted around the state. They are being conducted to gather information about your thoughts and suggestions for improving your choice, quality, and access to continuum of care services (i.e. home and community based services and nursing home care) for the elderly and people with disabilities. They are also being done to help identify ways to design and structure a single point of entry system to access these supports. In general we are considering ways to make it easier for you to maintain your independence as you age.*

*A focus group enables people to come together in one place to share opinions on a topic. Each of you is representing your own opinions; you do not need to view your comments as representative of an organization or a group of people. Please be honest and open as possible in your responses. Your anonymity will be protected. Your personal identifying information will be kept confidential and we request that you respect the*

*confidentiality of the other Focus Group participants. No one who is not working with the Real Choice Rebalancing grant will know who said what.*

*The results of the focus group will help the Real Choice Rebalancing staff and committees develop a plan. A report or summary will be generated from this focus group and will be shared with you and the project planning and steering committees. This information will be used along with the information from other focus groups to help the project committees develop a plan to improve your choice and access to continuum of services in your community and develop a single point of entry for these services. This information will also be shared with legislators and the governor in order to implement this plan state wide.*

*Throughout the focus group I will use the words services or helps; this is what professionals often call “continuum of care services.” Continuum of care services refer to the services or helps in your community that you use, have available, or would like to use that help you manage daily living needs and maximize your independence as you age. Some examples of these services or helps include: bathing, dressing, transferring, taking medications, other personal care services, transportation, home delivered meals, and homemaker services. These services are delivered in a variety of ways.*

*In order to gather your information accurately we will be making an audio recoding of the meeting along with written notes. Any summary information and reports that are developed from this focus group will be shared with you.*

*We will move quickly through a series of questions and should be done in about an hour and a half. At times you will be asked to first write down your own thoughts in response to the questions. Then each of you will be given an opportunity to share your thoughts.*

*Let's start by introducing ourselves.*

#### The Warm-Up: (5 minutes)

The facilitator will take a quick survey of the group to get an idea of what community services the participants have experienced.

**Script:** *What services or helps do you make use of in your community that allow you to live independently?*

The Questions (Please note that the information gathered through this study will also be built on the use of emergent questions and answers that develop due to the nature of the focus group/personal interview process.)

1. (10 minutes) Facilitator poses question. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the

room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

**Script:** *What additional services would you need to stay independent? Why aren't you currently using these services? What is preventing you from using these services?*

2. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

**Script:** *How do you feel about your current options and control of services and their availability? How could this be improved?*

3. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

**Script:** *Tell me how you found out about these helps or services? What worked? What didn't work? Why? What options were you given?*

4. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

**Script:** *If you were able to go to one place to find out about all of the available services in your community please describe what it would be like.*

5. (10 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

**Script:** *What importance do you place on these services?*

6. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:** How or what would you be willing to pay for your continuum of care services? What should the government pay for services?*

#### The Closing (10 Minutes)

The facilitator invites the group to note any last thoughts. Facilitator adjourns the session by thanking everyone for their participation and reminds them how the data will be used. They are given project contact information if they have any questions.

***Script:** Please take out a sheet of paper and note any last thoughts, comments, or things you wish to emphasize regarding the topics we discussed today to share with the Real Choice Rebalancing project committees. Thank you again for your participation. You will receive a summary of this session in the mail. You will also receive your stipend check as soon as possible. All of the information from this focus group will be reviewed and analyzed for a report to the Planning and Steering Committees. The Real Choice Rebalancing Grant hopes to finish all of the focus groups by the end of the year. With this input and the help of the project committees, a plan for improved Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota will be developed.*

### **Real Choice Rebalancing Grant: Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota**

#### **Focus Group / Personal Interviews B - Elderly Nursing Home Residents**

##### **Purpose Statement:**

to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities.

**Participants:** *Focus Group B - Elderly Nursing Home Residents*

##### **General information:**

- Number of Focus Groups: up to 8
- Various regions of North Dakota will be chosen for focus group sites including both rural and urban populations.
- Number at each meeting: up to 10
- Number to invite to each meeting: 20
- Total number of potential *Elderly Nursing Home Residents* invited: 160

##### **Attributes of focus group participants:**

- Elderly and/or persons with disabilities who currently reside in a nursing home

- Participants need to be cognitively intact and able to communicate with appropriate supports
- Age: 60 years and older
- Focus on those elderly who live in the nursing home, those who need personal care including ADLs and IADLs.
- Immediate family members or caregivers may also be present based on the nature of the situation
- Focus Groups will be held in the nursing home if possible so transportation will not be an issue for most participants. When possible some participants will be asked to attend a focus group at another community nursing home.
- Based on volunteer participation

Possible sources of invitations:

Various agencies will be contacted to assist with mailing invitations to the selected group. These agencies include: Long Term Care Association, regional nursing homes, Nursing Home Resident Councils, Centers for Independent Living, Older Americans Act Service Provides, Protection and Advocacy and other members of the *Real Choice Rebalancing* Steering and Stakeholder Committees.

These agencies will be given a letter of invitation from NDCPD at Minot State University. The agencies will be responsible for mailing out the letter. This will assure that confidentiality and HIPPA standards are upheld.

Stipends will be available for focus group and personal interview participants.

Snacks will be provided.

**Script, Questions, and Facilitator Instructions**

Arrival: (15 – 30 minutes prior to focus group start time)

Facilitator and assistant will greet invitees and help participants sign in when they arrive and verify their contact information. Participants will also be asked to fill out a W-9 Form and a *Real Choice Rebalancing* Stipend Form to receive their stipends.

The Opening: (15 minutes)

- Facilitator welcomes group and thanks them for coming, then introduces herself and the project and explains the purpose of the focus group.
- Participants introduce themselves to the rest of the group.
- Facilitator presents the agenda for the session.
- Reminder of confidentiality of the information.

***Script:***

*Hi, my name is \_\_\_\_\_.*

Welcome to the focus group for the Real Choice Rebalancing project and thank you for joining us. I will be facilitating the focus group today. \_\_\_\_\_ will be serving as a recorder for the focus group in order to record your information accurately.

As was detailed in your invitation letter this is one of a series of focus groups that are being conducted around the state. They are being conducted to gather information about your thoughts and suggestions for improving your choice, quality, and access to continuum of care services (i.e. home and community based services and nursing home care) for the elderly and people with disabilities. They are also being done to help identify ways to design and structure a single point of entry system to access these supports. In general we are considering ways to make it easier for you to maintain your independence as you age.

A focus group enables people to come together in one place to share opinions on a topic. Each of you is representing your own opinions; you do not need to view your comments as representative of an organization or a group of people. Please be honest and open as possible in your responses. Your anonymity will be protected. Your personal identifying information will be kept confidential and we request that you respect the confidentiality of the other Focus Group participants. No one who is not working with the Real Choice Rebalancing grant will know who said what.

The results of the focus group will help the Real Choice Rebalancing staff and committees develop a plan. A report or summary will be generated from this focus group and will be shared with you and the project planning and steering committees. This information will be used along with the information from other focus groups to help the project committees develop a plan to improve your choice and access to continuum of services in your community and develop a single point of entry for these services. This information will also be shared with legislators and the governor in order to implement this plan state wide.

Throughout the focus group I will use the words services or helps; this is what professionals often call "continuum of care services." Continuum of care services refer to the services or helps in your community that you use, have available, or would like to use that help you manage daily living needs and maximize your independence as you age. Some examples of these services or helps include: bathing, dressing, transferring, taking medications, other personal care services, transportation, home delivered meals, and homemaker services. These services are delivered in a variety of ways.

In order to gather your information accurately we will be making an audio recording of the meeting along with written notes. Any summary information and reports that are developed from this focus group will be shared with you.

*We will move quickly through a series of questions and should be done in about an hour and a half. At times you will be asked to first write down your own thoughts in response to the questions. Then each of you will be given an opportunity to share you thoughts. Let's start by introducing ourselves.*

**The Warm-Up:** (5 minutes)

The facilitator will take a quick survey of the group to get an idea of what community services the participants have experienced.

***Script:*** *What were the circumstances that brought you to the nursing home?*

**The Questions** (Please note that the information gathered through this study will also be built on the use of emergent questions and answers that develop due to the nature of the focus group/personal interview process.)

1. (10 minutes) Facilitator poses question. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:*** *If the needed services were available would you chose to live more independently and why?*

*What services or helps would you need to live more independently?*

2. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:*** *What continuum of care options were you given before you entered the nursing home?*

*How do you feel about your current options for services and their availability? How could this be improved?*

3. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:*** *Tell me how you found out about services. What worked? What didn't work? Why?*

4. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an

opportunity to share. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

*Script: If you were able to go to one place to find out about all of the available services in your community please describe what it would be like.*

5. (10 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: What importance do you place on these services?*

6. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: How or what would you be willing to pay for your services?  
What should the government pay for services?*

#### The Closing (10 Minutes)

The facilitator invites the group to note any last thoughts. Facilitator adjourns the session by thanking everyone for their participation and reminds them how the data will be used. They are given project contact information if they have any questions.

*Script: Please take out a sheet of paper and note any last thoughts, comments, or things you wish to emphasize regarding the topics we discussed today to share with the Real Choice Rebalancing project committees. Thank you again for your participation. You will receive a summary of this session in the mail. You will also receive your stipend check as soon as possible. All of the information from this focus group will be reviewed and analyzed for a report to the Planning and Steering Committees. The Real Choice Rebalancing Grant hopes to finish all of the focus groups by the end of the year. With this input and the help of the project committees a plan for improved Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota will be developed.*

#### **Real Choice Rebalancing Grant: Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota**

#### **Focus Group / Personal Interviews C - Younger Nursing Home Residents with Disabilities and their Families**

**Purpose Statement:**

to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities.

**Participants:** Group C- Younger Nursing Home Residents with Disabilities and their Families

**General information:**

- Number of Focus Groups: up to 8
- Various regions of North Dakota will be chosen for focus group sites including both rural and urban populations.
- Number at each meeting: up to 10
- Number to invite to each meeting: 20
- Total number of potential *Younger Nursing Home Residents with Disabilities and their Families* invited: 160

**Attributes of focus group participants:**

- Aging and/or persons with disabilities who currently reside in a nursing home
- Participants need to be cognitively intact and able to communicate with appropriate supports
- Age: 21 to 60 years old
- Focus on those with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- Immediate family members or caregivers may also be present based on the nature of the situation
- Focus Groups will be held in the nursing home if possible so transportation will not be an issue for most participants. When possible some participants will be asked to attend a focus group at another community nursing home.
- Based on volunteer participation

**Possible sources of invitations:** Various agencies will be contacted to assist with mailing invitations to the selected group. These agencies include: Long Term Care Association, regional nursing homes, Nursing Home Residents Councils, Centers for Independent Living, County and State lists of persons receiving services, Protection and Advocacy and other members of the *Real Choice Rebalancing* Steering and Stakeholder Committees. These agencies will be given a letter of invitation from NDCPD at Minot State University. The agencies will be responsible for mailing out the letter. This will assure that confidentiality and HIPPA standards are upheld.

Stipends will be available for these focus group and personal interview participants.

Snacks will be provided.

### **Script, Questions, and Facilitator Instructions**

Arrival: (15 – 30 minutes prior to focus group start time)

Facilitator and assistant will greet invitees and help participants sign in when they arrive and verify their contact information. Participants will also be asked to fill out a W-9 Form and a *Real Choice Rebalancing Stipend Form* in order to receive their stipends.

The Opening: (15 minutes)

- Facilitator welcomes group and thanks them for coming, then introduces herself and the project and explains the purpose of the focus group.
- Participants introduce themselves to the rest of the group.
- Facilitator presents the agenda for the session.
- Reminder of confidentiality of the information.

#### ***Script:***

*Hi, my name is \_\_\_\_\_...*

*Welcome to the focus group for the Real Choice Rebalancing project and thank you for joining us. I will be facilitating the focus group today. \_\_\_\_\_ is will be serving as a recorder for the focus group in order to record your information accurately.*

*As was detailed in your invitation letter this is one of a series of focus groups that are being conducted around the state. They are being conducted to gather information about your thoughts and suggestions for improving your choice, quality, and access to continuum of care services (i.e. home and community based services and nursing home care) for the elderly and people with disabilities. They are also being done to help identify ways to design and structure a single point of entry system to access these supports. In general we are considering ways to make it easier for you to maintain your independence as you age.*

*A focus group enables people to come together in one place to share opinions on a topic. Each of you is representing your own opinions; you do not need to view your comments as representative of an organization or a group of people. Please be honest and open as possible in your responses. Your anonymity will be protected. Your personal identifying information will be kept confidential and we request that you respect the confidentiality of the other Focus Group participants. No one who is not working with the Real Choice Rebalancing grant will know who said what.*

*The results of the focus group will help the Real Choice Rebalancing staff and committees develop a plan. A report or summary will be generated from this focus group and will be shared with you and the project planning and steering committees. This information will be used along with the information from other focus groups to help the project committees develop a plan to improve your choice and access to continuum of services in your*

*community and develop a single point of entry for these services. This information will also be shared with legislators and the governor in order to implement this plan state wide.*

*Throughout the focus group I will use the words services or helps; this is what professionals often call “continuum of care services.” Continuum of care services refer to the services or helps in your community that you use, have available, or would like to use that help you manage daily living needs and maximize your independence as you age. Some examples of these services or helps include: bathing, dressing, transferring, taking medications, other personal care services, transportation, home delivered meals, and homemaker services. These services are delivered in a variety of ways.*

*In order to gather your information accurately we will be making an audio recoding of the meeting along with taking written notes. Any summary information and reports that are developed from this focus group will be shared with you.*

*We will move quickly through a series of questions and should be done in about an hour and a half. At times you will be asked to first write down your own thoughts in response to the questions. Then each of you will be given an opportunity to share you thoughts.*

*Let's start by introducing ourselves.*

#### The Warm-Up: (5 minutes)

The facilitator will take a quick survey of the group to get an idea of what community services the participants have experienced.

**Script:** *What were the circumstances that brought you to the nursing home?*

The Questions (Please note that the information gathered through this study will also be built on the use of emergent questions and answers that develop due to the nature of the focus group/personal interview process.)

1. (10 minutes) Facilitator poses question. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

**Script:** *If the needed services were available would you chose to live more independently and why?*

*What services or helps would you need to live more independently?*

2. (10 minutes) Facilitator poses question. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:** Previously what community services did you make use of that allowed you to live more independently?*

3. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:** What service options were you given before you entered the nursing home? How do you feel about your current options for services and their availability? How could this be improved?*

4. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

***Script:** Tell me how you found out about services. What worked? What didn't work? Why?*

5. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

***Script:** If you were able to go to one place to find out about all of the available services in your community please describe what it would be like.*

6. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a chance. This will be continued around the room until all comments have been exhausted.

***Script:** What importance do you place on these services?  
How or what would you be willing to pay for your services?  
What should the government pay for services?*

### The Closing (10 Minutes)

The facilitator invites the group to note any last thoughts. Facilitator adjourns the session by thanking everyone for their participation and reminds them how the data will be used. They are given project contact information if they have any questions.

**Script:** Please take out a sheet of paper and note any last thoughts, comments, or things you wish to emphasize regarding the topics we discussed today to share with the Real Choice Rebalancing project committees. Thank you again for your participation. You will receive a summary of this session in the mail. You will also receive your stipend check as soon as possible. All of the information from this focus group will be reviewed and analyzed for a report to the Planning and Steering Committees. The Real Choice Rebalancing Grant hopes to finish all of the focus groups by the end of the year. With this input and the help of the project committees a plan for improved Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota will be developed.

**Real Choice Rebalancing Grant: Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota**

**Focus Group / Personal Interviews D - Family members who have been faced with a crisis situation when seeking continuum of care services for elderly or people with disabilities**

**Purpose Statement:**

to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities.

**Participants:** Group D - Family members who have been faced with a crisis situation when seeking continuum of care services for elderly or people with disabilities

**General information:**

- Number of Focus Groups: up to 8
- Various regions of North Dakota will be chosen for focus group sites including both rural and urban populations.
- Number at each meeting: up to 10
- Number to invite to each meeting: 20
- Total number of potential Family members who have been faced with a crisis situation when seeking continuum of care services for elderly or person with a disability invited: 160

**Attributes of focus group participants:**

- Close family members who have been faced with a crisis situation when seeking continuum of care services for elderly or person with a disability
- Age: 21 years and older

- Focus on those who have family members with physical disabilities and long term illness, need for personal care with ADLs and IADLs
- People who have transportation to the meeting sight
- Preferably participants not more than approximately 40 miles from the meeting sight

Possible sources of invitations: Various agencies will be contacted to assist with mailing invitations to the selected group. These agencies include: Long Term Care Association, regional nursing homes, Nursing Home Residents Councils, Centers for Independent Living, County and State lists of persons receiving services, Senior Info Line, RASPs, Protection and Advocacy, and other members of the *Real Choice Rebalancing* Steering and Stakeholder Committees.

These agencies will be given a letter of invitation from NDCPD at Minot State University. The agencies will be responsible for mailing out the letter. This will assure that confidentiality and HIPPA standards are upheld.

Stipends will be available for focus group and personal interview participants.

Snacks will be provided.

### **Script, Questions, and Facilitator Instructions**

Arrival: (15 – 30 minutes prior to focus group start time)

Facilitator and assistant will greet invitees and help participants sign in when they arrive and verify their contact information. Participants will also be asked to fill out a W-9 Form and a *Real Choice Rebalancing* Stipend Form in order to receive their stipends.

The Opening: (15 minutes)

- Facilitator welcomes group and thanks them for coming, then introduces herself and the project and explains the purpose of the focus group.
- Participants introduce themselves to the rest of the group.
- Facilitator presents the agenda for the session.
- Reminder of confidentiality of information

#### ***Script:***

*Hi, my name is \_\_\_\_\_.*

*Welcome to the focus group for the Real Choice Rebalancing project and thank you for joining us. I will be facilitating the focus group today. \_\_\_\_\_ will be serving as a recorder for the focus group in order to record your information accurately.*

*As was detailed in your invitation letter this is one of a series of focus groups that are being conducted around the state. They are being conducted to gather information about your thoughts and suggestions for improving your choice, quality, and access to*

*continuum of care services (i.e. home and community based services and nursing home care) for the elderly and people with disabilities. They are also being done to help identify ways to design and structure a single point of entry system to access these supports. In general we are considering ways to make it easier for you to maintain your independence as you age.*

*A focus group enables people to come together in one place to share opinions on a topic. Each of you is representing your own opinions; you do not need to view your comments as representative of an organization or a group of people. Please be honest and open as possible in your responses. Your anonymity will be protected. Your personal identifying information will be kept confidential and we request that you respect the confidentiality of the other Focus Group participants. No one who is not working with the Real Choice Rebalancing grant will know who said what.*

*The results of the focus group will help the Real Choice Rebalancing staff and committees develop a plan. A report or summary will be generated from this focus group and will be shared with you and the project planning and steering committees. This information will be used along with the information from other focus groups to help the project committees develop a plan to improve your choice and access to continuum of services in your community and develop a single point of entry for these services. This information will also be shared with legislators and the governor in order to implement this plan state wide.*

*Throughout the focus group I will use the words services or helps; this is what professionals often call "continuum of care services." Continuum of care services refer to the services or helps in the community that your family members uses, has available, or would like to use that help him/her manage daily living needs and maximize independence as they age. Some examples of these services or helps include: bathing, dressing, transferring, taking medications, other personal care services, transportation, home delivered meals, and homemaker services. These services are delivered in a variety of ways.*

*In order to gather your information accurately we will be making an audio recoding of the meeting along with taking written notes. Any summary information and reports that are developed from this focus group will be shared with you.*

*We will move quickly through a series of questions and should be done in about an hour and a half. At times you will be asked to first write down your own thoughts in response to the questions. Then each of you will be given an opportunity to share you thoughts. Let's start by introducing ourselves.*

**The Warm-Up: (5 minutes)**

The facilitator will take a quick survey of the group to get an idea of what community services the participants have experienced.

*Script: What services or helps does your family member currently use?*

The Questions (Please note that the information gathered through this study will also be built on the use of emergent questions and answers that develop due to the nature of the focus group/personal interview process.)

1. (10 minutes) Facilitator poses question. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: What additional services does your family member need to stay more independent? Why aren't they currently using these services?*

2. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: How do you feel about the current options and control of services and their availability? How could this be improved?*

3. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: Tell me how you found out about the continuum of care services for your family member. What worked? What didn't work? Why? What options were you given?*

4. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

*Script: If you were able to go to one place to find out about all of the available services in your community for your family member please describe what it would be like.*

*Please describe how importance is it to have a person available whose job it is to advise you regarding continuum of care options?*

5. (15 minutes) Facilitator poses question. Participants will first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had an opportunity to share. This will be continued around the room until all comments have been exhausted.

*Script: What importance do you place on these services?*

*How or what would you or your family member be willing to pay for these services?*

*What should the government pay for services?*

### The Closing (10 Minutes)

The facilitator invites the group to note any last thoughts. Facilitator adjourns the session by thanking everyone for their participation and reminds them how the data will be used. They are given project contact information if they have any questions.

*Script: Please take out a sheet of paper and note any last thoughts, comments, or things you wish to emphasize regarding the topics we discussed today to share with the Real Choice Rebalancing project committees. Thank you again for your participation. You will receive a summary of this session in the mail. You will also receive your stipend check as soon as possible. All of the information from this focus group will be reviewed and analyzed for a report to the Planning and Steering Committees. The Real Choice Rebalancing Grant hopes to finish all of the focus groups by the end of the year. With this input and the help of the project committees a plan for improved Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota will be developed.*

### ***Real Choice Rebalancing Grant: Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota***

### **Focus Group / Personal Interviews E - Providers**

#### **Purpose Statement:**

to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access of long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and persons with disabilities.

**Participants:** *Group E - Providers*

#### **General information:**

- o Number of Focus Groups: up to 4

- Various regions of North Dakota will be chosen for focus group sites including both rural and urban populations.
- Number at each meeting: up to 10
- Number to invite to each meeting: 20
- Total number of potential *Providers* invited: 160

Attributes of focus group attendees:

- Providers of continuum of care services
- Focus on those who refer or provide continuum of care services for adults with physical disabilities and long term illness, or elderly who need personal care including ADLs and IADLs
- People who have transportation to the meeting sight
- Preferably providers not more than approximately 40 miles from the meeting sight

Possible sources of invitations: Various agencies will be contacted to assist with mailing invitations to the selected group. These agencies include: statewide and regional lists of referral or provider agencies across the continuum of care including members of the *Real Choice Rebalancing* Steering and Stakeholder Committees. These agencies will be given a letter of invitation from NDCPD at Minot State University. The agencies will be responsible for mailing out letters to participants. This will assure that confidentiality and HIPPA standards are upheld.

Snacks will be provided.

### **Script, Questions, and Facilitator Instructions**

Arrival: (15 – 30 minutes prior to focus group start time)

Facilitator and assistant will greet invitees and help participants sign in when they arrive and verify their contact information

The Opening: (15 minutes)

- Facilitator welcomes group and thanks them for coming, then introduces herself and the project and explains the purpose of the focus group.
- Participants introduce themselves to the rest of the group.
- Facilitator presents the agenda for the session.

***Script:***

*Hi, my name is \_\_\_\_\_.*

*Welcome to the focus group for the Real Choice Rebalancing project and thank you for joining us. I will be facilitating the focus group today. \_\_\_\_\_ will be serving as a recorder for the focus group in order to record your information accurately.*

*As was detailed in your invitation letter this is one of a series of focus groups that are being conducted around the state. They are being conducted to gather information about your thoughts and suggestions for improving your choice, quality, and access to continuum of care services (i.e. home and community based services and nursing home care) for the elderly and people with disabilities. They are also being done to help identify ways to design and structure a single point of entry system to access these supports. In general we are considering ways to make it easier for elderly and people with disabilities to maintain independence as they age.*

*A focus group enables people to come together in one place to share opinions on a topic. Each of you is representing your own opinions; you do not need to view your comments as representative of an organization or a group of people. Please be honest and open as possible in your responses. Your anonymity will be protected. Your personal identifying information will be kept confidential and we request that you respect the confidentiality of the other Focus Group participants. No one who is not working with the Real Choice Rebalancing grant will know who said what.*

*The results of the focus group will help the Real Choice Rebalancing staff and committees develop a plan. A report or summary will be generated from this focus group and will be shared with you and the project planning and steering committees. This information will be used along with the information from other focus groups to help the project committees develop a plan to improve your choice and access to continuum of services in your community and develop a single point of entry for these services. This information will also be shared with legislators and the governor in order to implement this plan state wide.*

*Throughout the focus group I will use the term “continuum of care services.” When I use this term I am referring to the services and helps that you provide, have available, or would like to have available in your community in order to make individuals better able to live in their homes or more independently. These continuum of care services help individuals manage daily living needs and maximize independence as they age. Some examples of these services or helps include: bathing, dressing, transferring, taking medications, other personal care services, home delivered meals, and homemaker services. These services are delivered in a variety of ways.*

*In order to gather your information accurately we will be making an audio recoding of the meeting along with taking written notes. Any summary information and reports that are developed from this focus group will be shared with you.*

*We will move quickly through a series of questions and should be done in about an hour and a half. At times you will be asked to first write down your own thoughts in response to the questions. Then each of you will be given an opportunity to share you thoughts.*

*Let's start by introducing ourselves.*

The Warm-Up: (5 minutes)

The facilitator will take a quick survey of the group to get an idea of what community services the participants have experienced.

*Script: What community continuum of care supports do you refer to or provide? Generally who do you provide these services to?*

The Questions (Please note that the information gathered through this study will also be built on the use of emergent questions and answers that develop due to the nature of the focus group/personal interview process.)

1. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a chance. This will be continued around the room until all comments have been exhausted.

*Script: How do you feel about the current options for services and their availability? How could this be improved?*

2. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a chance. This will be continued around the room until all comments have been exhausted.

*Script: Tell me how people find out about or access your continuum of care services? What works? What doesn't work? Why?*

3. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a chance. This will be continued around the room until all comments have been exhausted. After this the facilitator will ask the group to note the top five most important factors.

*Script: If consumers and family members were able to go to one place to find out about all of the available services in your community describe what it would be like.*

*Describe the importance of a person available whose job it would be to advise consumers regarding continuum of care options.*

4. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a

chance. This will be continued around the room until all comments have been exhausted.

***Script:** How might you be better able to offer services if there was an improved system for accessing services?*

5. (15 minutes) Facilitator poses question. Participants should first record thoughts by themselves on a piece of paper. The facilitator will then write the comments on a flip cart, taking one comment at a time until everyone in the room has had a chance. This will be continued around the room until all comments have been exhausted.

***Script:** How or what do you think consumers would be willing to pay for their services? What should the government pay for services?*

#### The Closing (10 Minutes)

The facilitator invites the group to note any last thoughts. Facilitator adjourns the session by thanking everyone for their participation and reminds them how the data will be used. They are given project contact information if they have any questions.

***Script:** Please take out a sheet of paper and note any last thoughts, comments, or things you wish to emphasize regarding the topics we discussed today to share with the Real Choice Rebalancing project committees. Thank you again for your participation. You will receive a summary of this session in the mail. You will also receive your stipend check as soon as possible. All of the information from this focus group will be reviewed and summarized for a report to the Planning and Steering Committees. The Real Choice Rebalancing Grant hopes to finish all of the focus group by the end of the year. With this input and the help of the project committees a plan for improved Choice and Self-directed community Resource Delivery for the Elderly and People with Disabilities in North Dakota will be developed.*

